Diabetes in the young: technology, engagement and context

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Abstract
Over the last three decades, while insulin replacement in type 1 diabetes in the young remains fundamental, the methods of delivering this therapy have changed dramatically.

‘Intensive insulin’ therapy offers the best outcome, in terms of glycaemia and long-term health, and a shift to multiple injection therapy and pumps has become the approach promoted early after diagnosis. A recent recognition is the sustained effect of near-normal glycaemia from diagnosis (‘metabolic memory’), achieved through strict glucose targets and dose adjustment of insulin for carbohydrate.

To use the developing technology of type 1 diabetes requires considerable motivation from patients and their families with a need for a parallel support programme from a multidisciplinary team. The components of successful adherence to the management regimens are a matching of health beliefs, attuned communication and reciprocity between those with diabetes, their families and health professionals. Innovative approaches are required to deliver these components within a health service.

For many patients across the world, the context in which they live markedly affects the treatment offered and the acceptance of the condition. With the increasing incidence of type 1 diabetes the difficulties encountered in different environments and social settings are considerable, requiring support and direction from an international ‘diabetes family’.

Arnold Bloom, BDA/DUK and the changing face of diabetes
‘Arnold Bloom understood the need to underpin best clinical practice with meticulous observation and robust research, but he also recognised the essential contribution of wisdom derived from experience – combining science with the art of medicine.’ Despite the ‘spectacles and phenomena’ of modern therapies and the potential of new clinical strategies, Arnold Bloom understood that diabetes ‘is a human disorder and as such subject to the capriciousness of human behaviour’. These are the words of Professor Ken Shaw from his 2011 Arnold Bloom State of the Art Lecture:1 heart-felt admiration from a student to his mentor. While I was never directly linked with Arnold Bloom, I feel strongly that his ideas and thinking influenced, as for many UK diabetologists, my own programme of work and discovery in the management and support of young people with diabetes and their families.

As a medical student at University College Hospital, London, in the early 1970s I was taught by Arnold Bloom at the Whittington Hospital. At that time diabetes held little attraction. It seemed a ‘muddle’ of definitions, hard to treat and a depressing condition with a poor outlook: quite unappealing to a young medical student. However, by the early 1980s by the time I had undertaken my basic paediatric training, and even with being beguiled by the mesmeric world of invasive neonatology, I was stimulated by and joined in a ‘new world’ of diabetes. My own mentor was David Baum, one of the first UK paediatricians to establish a programme of research fellows and translational research in diabetes in this age group. But my increasing excitement for the area was enhanced majorly by people active in the British Diabetic Association at the time, such as Arnold Bloom, George Alberti, Harry Keen and Robert Tattersall. Diabetes seemed to be changing. Clinical and scientific meetings were full of new theories and constructs, approaches and visions, and these needed to be offered to young people with type 1 diabetes and their families, with the help of a committed multidisciplinary team.
diabetes. During this time as a young research fellow in Oxford I met Arnold Bloom again, through David Baum who knew him personally, and who shared a similar encompassing and holistic approach to improving the lives of people with diabetes.

This was an exciting period between 1972 (the year of the initiation of the BDA UK National Diabetes Register) and 1993 (the year of the publication of DCCT) of the understandings in the epidemiology of diabetes, invention of new technologies (strips and meters, pens, pumps), an intensive approach to the management of insulin requiring diabetes and the appreciation of the issues of living with diabetes, and a more rigorous behavioural intervention for children, adolescents and their families. While it could be argued that the ‘hard yards of diabetes’ still existed and that there had been no paradigm shift on the road to successful diabetes management since the discovery of insulin in 1921, an overwhelming optimism existed in the areas of potential cure, easier management and better quality of life for young people on a lifelong programme of insulin replacement. A tipping point was upon us, and I believe we are progressing through that inflection at considerable speed. Arnold Bloom’s philosophy of critical analysis with a structured methodical approach to the evaluation of managing diabetes is beginning to pay enormous dividends for large numbers of people who develop diabetes at a young age.

**Defining the problem**

In 1975, Arnold Bloom, along with TM Hayes and Robert Gamble, published the first report of the BDA UK Register of new patients with diabetes aged 0–15 years in Great Britain and Ireland, with over 2000 cases notified in the first two years. Continuing work on the register formed the basis of his 1982 Banting Lecture to the BDA and the project spawned an era of major epidemiological observations leading to the Bart’s–Windsor–Oxford Study and intervention trials such as ENDIT.

While the ‘cure’ of diabetes through ‘vaccination’, environmental change or immunological intervention has run aground in the recent years, the instigation of a local and national validated Register of new and current patients as developed by Arnold Bloom opened up a whole area of activity that is still developing today. By knowing the scale and details of the problem, the outcome can be defined and, perhaps more importantly, the performance of the health care systems deployed to support people with diabetes can be measured against standard benchmarks. Assessing the quality performance of the NHS in managing diabetes depends on that initial challenge of documenting your population.

NICE and SIGN brought together the body of evidence at the beginning of the new millennium outlining in clinical guidelines the standards that should be set for the management of diabetes in the young and the best practice strategies that should be employed. High standards were set and, despite major areas that lacked evidence-based research, definitive ways of managing young people with type 1 diabetes were stated unequivocally.

Sadly, the initial audits of outcome in the UK demonstrated our poor outcome and performance. The DIABAUD Programme for the Care of the Young with Diabetes (SSGCYD) showed that the majority of young people, especially older teenagers, were ‘way off target’ in terms of glycaemic control (DIABAUD 1&2); that there was no significant improvement over 10 years up to 2005 (DIABAUD 3), and that there was significantly better outcome in certain parts of Europe (Hvidøre Study Group publications). This has been re-stated recently in national UK and Scottish Survey data (see Figure 1). The latter have shown that the groups with the ‘worst’ outcome are older teenagers and young adults.

A great deal of effort has been placed in this period of ‘transition’ with attempts to describe the correct approach and format required, and how to support the young adult to transfer from paediatric care to the adult service. Perhaps a more fruitful way forward would be in not accepting the change from a child orientated to an adult medicine service, but to continue a ‘seamless type I service’ that copes...
with the needs of individuals by a more flexible and integrated multidisciplinary team (MDT).

Comparisons of data sets are fraught with difficulties (biased selection of cohorts; non-total population assessment; comparison of different methods of analysis of glycated haemoglobin; comparison of different age and sex groups; lack of details of employment of health care strategies). Such comparisons must be undertaken carefully and collaboratively with the desire to support stretched clinical teams, rather than be used as a stick to punish/name and shame. However, there is a general acceptance that young people with diabetes in the UK do not fare as well as comparable groups in other parts of Western Europe.

This message has undoubtedly been received over the last few years by health professionals in the UK responsible for advising and supporting young families. Efforts are being taken over a broad front – intensive insulin therapy (see below), behavioural support and, more recently, quality and safety measures employed to improve the outcomes of young people with diabetes. In Tayside, we have employed a Quality Improvement approach, designed firstly by identification of the drivers necessary to improve glycaemic control and then instigated by the multidisciplinary clinical team to make appropriate changes needed in service delivery and strategy development. This approach, coupled with formal assessment and evaluation through routine data collection, appears to be having a significant effect on our clinical outcome.9

On an international basis the ‘Sweet Programme’ under the direction of Thomas Danne and colleagues and supported by the International Society for Pediatric and Adolescent Diabetes is a major effort in creating ‘Centres of Reference’ with the objective to inspire further improvement in health outcome for young people with diabetes.10

This really is the ‘hard yards’ of diabetes: ‘shifting the glycaemic control distribution curve to the left’. This requires the MDT to continually adjust their management strategies and persistently support young people and their families in self-managing their diabetes on a 24-hour basis. It appears that, by using all the available tools, small gains are taking place but it is agreed that for the majority it still requires considerable effort.

**Being more intensive**

While the fundamental delivery of insulin has not changed since its first production – subcutaneously and into the peripheral circulation by needle injection – the organisation and systems for maximising its potential have been refined over the years. Over the last decade ‘intensive insulin therapy’ using multiple daily injections has become established as the standard therapy even in young children. While pre-mixed insulin in easily usable pen systems appealed to patients, it is accepted that this non-physiological replacement left patients at significant risk for long-term vascular complications. A basal-bolus regimen with pre-meal rapid insulin and daily long-acting insulin is considered the best option, provided it is coupled with frequent capillary blood glucose monitoring and, importantly, adjustment of each injection dose to the carbohydrate content of the meal. Overall MDI versus, so-called, conventional insulin therapy achieves lower glycated haemoglobin in routine clinical practice.11

Interestingly, however, in the Hvidøre Study Group8 and the SSGCYD7 analysis of the factors driving lower glycaemia, specific insulin regimens did not figure as a factor, but more in the MDT philosophy in the context of how the regimens were deployed – that is, tight control from the onset, target setting for glycaemia, attention to detail around diet, exercise and other lifestyle issues, backed up by effective communication between the patients and the health care professionals.

A major re-think in the care of patients has been the re-introduction of carbohydrate assessment, with the teaching of meal content and advice on insulin dosing in relation to age, duration of diabetes, time of day as well meal content. This requires expertise and experience from dietitians and other health professionals, and is a practice that has had to be re-learnt by many and initiated by new practitioners who have again become key members of the MDT.

In Tayside, we have now instigated a ‘glucocentric’ practice from diagnosis. Following evaluation by the MDT we embarked on a policy of insulin adjustment to carbohydrate content from the first few days after diagnosis, aided by the use of a bolus calculator, strict pre-meal blood glucose targets and teaching aids for carbohydrate substance of the meal. Despite these difficult concepts being introduced to patients and families at a time of major emotional stress, we have had a significant improvement in the glycaemic control in the first six months with our patients (see Figure 2). From various studies including the Hvidøre Study Group12 it is projected that this tightening of control will have a ‘metabolic memory’ effect on future glycaemia and add to the improving outlook for young people with diabetes. Whether the effect is physiological (preservation of beta-cell mass/improved insulin resistance or behavioural by ‘picking up good habits’) remains to be seen.

This places a significant burden on the patient and their family to remain motivated to take on the challenge and burden of self-management of diabetes. For many years, erratic control of glycaemia (swinging levels with clinical hypoglycaemia) and frequent episodes of diabetic ketoacidosis were seen regularly in many patients, with several cases of ‘brittle diabetes’ described in each clinic. ‘Unusual’ diabetes was a suggested cause, with various insulin allergies, sensitivity or resistance syndromes being the reason behind such difficulties.

My work with Andrew Morris and Ray Newton laid open the real reason for erratic glycaemic control in most young people. Non-adherence to insulin therapy had been suspected by most clinicians, but without any specific proof. Our work using the unique DARTS data

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set in Tayside showed that 25% of young people (mostly the teenagers) omitted around 30% of their prescribed insulin dose over one year. The capriciousness of human behaviour, so wisely understood by Arnold Bloom, was expressed strongly by many young adults with this lifelong condition, with the period of transition from family support of diabetes to the young person’s independent care of diabetes, remaining the most challenging.

'Digital diabetes'
The use of new ‘tools’ has always been part of the approach to the management of diabetes but, in the last decade, diabetes strategies in young people with type 1 diabetes have moved distinctly into the digital age: insulin delivery systems (pens and pumps), glucose monitoring machines, continuous sensors, electronic diabetes diaries, mHealth communication systems, backed up by electronic patient health records shared by patients and health professionals.

The use of pumps in the UK has had a stuttering history, despite being first described by Pickup and his team in the late 1970s. The deployment of the systems were delayed in the UK following a poor clinical outcome with first generation pumps, but in the last five years, backed up by consistent and safe technology and evidence-based guidelines, the use of pumps is becoming a standard part of therapy. Paediatric teams have led the way in this development in the UK, and indeed the very young child with diabetes is seen as an exemplar patient to benefit from pump therapy. Over the last 10 years, in Tayside, we have placed nearly 50% of our patients onto pump therapy and incorporated the system in our routine strategy for diabetes in the young.

Continuous sensors are going the same way and the ‘semi-closed loop’ system is now available by combining pumps, sensor feedback and data analysis. There is, however, an acceptance that irregular use in everyday practice is inefficient, with teenagers unhappy about regular wearing of the systems. Major changes are likely in sensor technology and a ‘dual sensor’ (single system for delivery of insulin and glucose monitoring) would change the landscape. A series of translational and long-term follow up clinical studies will be needed to assess the value and usability of the new generation sensor systems.

The other area of rapid development in the near future is in the feedback of data from these systems to the patient and health professional and the interpretation of the glucose results and pump settings. Using the world of mobile communication and improved design as well as a better understanding of the markers of blood glucose variability, a cleaner and clearer feedback in results – distinct from the current overwhelming mess of data supplied by most pump and sensor manufactures – will be available, helping to motivate patients as well as direct the necessary clinical changes.

The final approaches to a fully operational ‘closed-loop’ pump system have moved forward recently. Success in the development of sensor-augmented pumps and accurate low glucose suspend systems has supported development in algorithm driven systems. Hovorka and his team in Cambridge, under the direction of David Dunger, are one of a small number of dedicated research groups around the world working on the ‘artificial pancreas’ and recent data from overnight systems appear very promising. When and how they are introduced into routine practice is open to question, but they are now in sight, and not just on the horizon.

Interestingly, in a Symposium on the Artificial Pancreas at the ISPAD 2013 Conference in Gothenburg, Carlo Acerini from the group raised the issue that as with any therapeutic device and intervention it will come with a price for some people. Although in the future, if used correctly it is likely to produce excellent blood glucose control for some, it will not be the answer for others, and may raise emotional reactions and responses that will require support and direction from a dedicated clinical team.

This has been seen when reviewing the use of current pumps in everyday clinical practice. In a recent review, John Pickup showed that pumps undoubtedly produce lower blood glucose levels to begin with, but the effect in both children and adults wanes over time. This mimics the effect seen in the original DCCT study. However, as the EDIC study has shown the use of pumps, possibly through reduction in glucose variability, has a sustaining effect on long-term vascular complications of diabetes.
Education to engagement

While type 1 diabetes is a human disorder that requires constant self-management and the time spent by patients with their health professionals is a short period in their lives, the giving of advice, direction and support is a vital role for the MDT.

The transfer of knowledge about diabetes and its practical management is a necessity for the patients and the foundation of their experience with diabetes. The MDT delivers education in a planned programme as well as opportunistically, and over the years a plethora of excellent education material has been developed for a variety of media to suit the different ages and learning capabilities of patients. More recently, structured education programmes have been introduced to refresh or re-stimulate patients, particularly when taking up a new form of treatment.

However, education alone does not help patients to motivate themselves over a lifetime of diabetes self-management. Social cognitive theory explains that people do not learn new behaviours solely by trying them and either succeeding or failing but by observing others, with the environment, behaviour and cognition all as the chief factors in influencing development in a reciprocal triadic relationship. Various studies have demonstrated that improved glycaemic control is significantly reflected in measures of effective behaviour learning according to the social cognitive theory, such as self-efficacy. In other words, giving education alone is not enough; other support mechanisms must be in place to take forward the education programmes.

In a series of observations over 15 years, Alexandra Greene from our group outlined a basis for the effective transfer of knowledge and, more importantly, positive action by the patient. Based largely on watching patient–health professional interactions in consultations in a variety of different clinical, environmental and geographical settings and using an anthropological approach to the analysis of the observations, she outlined a model of effective support and communication based on three pillars: matching health beliefs, reciprocal communication, and trust.

The challenge is how to create these as part of the care strategy adopted by the MDT, within the resources provided by the NHS. Undoubtedly, the combining of ‘science and art’, as Arnold Bloom suggested, is fundamental but other approaches may have benefits and need exploring in a structured way. Effective communication requires a two-way model and not only does effort need to be given to training staff in successful communication approaches (such as motivational interviewing), but also the patient will need direction and instruction.

We are exploring techniques (such as video interaction guidance [VIG]) commonly used in social work and positive psychology to improve the communication process and positive change, by engaging patients to take on the difficult task of self-management over time. We have also used mobile health approaches (‘Sweet Talk’) to deliver a structured behavioural support system, which appears to have a major impact on measures such as self-efficacy.

Further work is required in this area to maximise how we engage particular teenagers and young adults. This will still be required even with the anticipated technological advances in care over the next decade. ‘The capriciousness of human behaviour’, as Arnold Bloom recognised, requires constant vigilance and understanding, and is a major function of the MDT.

Contextualising diabetes

These thoughts and ideas have stemmed from a practising paediatric diabetologist in the UK, but have been heavily influenced by my fortune over the last 20 years to be part of the International Society for Pediatric and Adolescent Diabetes (ISPAD), and honoured to be appointed as its President in 2012. The dialogue with those with diabetes and active clinical scientists across the world has had a major influence on my practice and approach, and I have realised that there are always different and emerging ways to approach the delivery of care to young people with diabetes.

ISPAD has also shown me that despite our continual discussions around the resources in the NHS required to undertake the delivery of health care for young people with diabetes, the availability of free insulin and expertise from professionals on the management of diabetes must not be taken for granted. We are in the ‘first world’ for diabetes and must strive appropriately; we must not forget those who are disadvantaged and desperate. Through ISPAD and the International Diabetes Federation linked projects such as Life for a Child (www.idf.org/lifeforachild), I recognise that a large percentage of young people with diabetes in the world are in a desperate and difficult position with basic medical needs unfulfilled. I would ask all to consider joining with us as a resource to help in any way possible: for further information see www.ispad.org.

In conclusion, there have been major changes in the management of diabetes in the young since Arnold Bloom started the UK BDA Diabetes Registry over 40 years ago. The use of new digital technologies is transforming the care strategies and leading to a better outcome, and helping young people and their families take on the ‘hard yards’ of diabetes self-care.

As Arnold Bloom so eloquently stated, human behaviour will always operate in this difficult to manage disease, attention to the well-being of our patients will always form a major part of the service we offer, and the combination of ‘science and art’ will continue to be at the heart of our practice.

Declaration of interests

There are no conflicts of interest declared.

References

References are available in Practical Diabetes online at www.practicaldiabetes.com.
References